



# MEDIA KIT



# TABLE OF CONTENTS

What is Prader-Willi Syndrome?	3
About Prader-Willi Syndrome Association   USA	4
What We Do - Our Work	5
Our Team & Leadership	6
Testimonials & Success Stories	7
Marketing Analytics	8-9
Sub-Brands of PWSA   USA	10
PWSA   USA Events	11
2026 Editorial Calendar	12
Learn More About Our Work	13







# WHAT IS PWS?



## Insatiable Hunger

Individuals with PWS experience an insatiable hunger, which can lead to overeating and obesity.



## Behavioral Issues

PWS is often associated with temper outbursts, obsessive-compulsive tendencies, and anxiety.



## Low Muscle Tone

Infants with PWS often have low muscle tone, causing feeding difficulties and delayed milestones.

[LEARN MORE](#)



# WHO WE ARE

## OUR HISTORY

The Prader-Willi Syndrome Association | USA (PWSA | USA) is a national nonprofit organization dedicated to supporting individuals and families affected by Prader-Willi syndrome (PWS), a rare genetic disorder. Since our founding in 1975, we have become the leading voice for PWS awareness, support, education, and advocacy across the United States.

## OUR MISSION

Our mission is to enhance the quality of life for those affected by PWS through support, research, and advocacy. We provide essential resources, raise awareness, and fund research initiatives aimed at understanding PWS and improving treatment options.

[LEARN MORE](#)







# WHAT WE DO

## **FAMILY SUPPORT**

We offer compassionate guidance to families navigating the challenges of living with PWS. Our support includes connecting families with medical professionals, resources, and peer networks to help them manage daily care.

## **ADVOCACY & AWARENESS**

PWSA | USA actively advocates for policies that improve the lives of individuals with PWS. We work closely with lawmakers, healthcare professionals, and the general public to raise awareness and understanding of PWS.

## **EDUCATION & RESOURCES**

We provide a wide range of educational materials, workshops, and training to equip caregivers, educators, and medical professionals with the knowledge needed to support those affected by PWS.

## **RESEARCH & INNOVATION**

We are committed to advancing research on Prader-Willi syndrome. Through funding research initiatives and supporting clinical trials, we strive to move closer to effective treatments.



# OUR TEAM & LEADERSHIP



**Stacy Ward, MS, BCBA**  
 PWSA | USA CEO



**Marguerite Rupnow, MBA**  
 Board of Directors, Chair



**Tina Ihlenfeld, MBA**  
 Board of Directors, Treasurer



**Denise Servais**  
 Board of Directors, Secretary

[READ CEO BIO](#)

[READ BOARD MEMBER BIOS](#)

[READ STAFF BIOS](#)

## PWSA | USA STAFF

*Listed in alphabetical order*

**Charles Conway, Jr.**, Executive Administrative Assistant  
**Angela Frazier**, Events Coordinator  
**Anne Fricke**, Marketing & Communications Coordinator  
**Lynn Garrick, MSN, RN**, Medical/Research Coordinator  
**Andrea Hughes**, Database Coordinator  
**Carrie Iljevich**, Director of Marketing & Communications  
**Sarah Kasaby**, Information & Referral Specialist  
**Dorothea Lantz**, Director of Community Engagement  
**Amy Maust, CPA**, Director of Accounting

**Katie Martinez**, Fundraising Coach: Team & Online Events  
**Melanie Zalman**, Director of Development  
**Kristi Rickenbach**, Parent Support Coordinator  
**Kristen Starkey**, Accounting Clerk  
**Elaine Towle**, Advocacy Specialist  
**Kim Tula, MS, CSW**, Senior Family Support Counselor and Trainer  
**Stacy Ward, MS, BCBA**, CEO

## PWSA | USA BOARD OF DIRECTORS

*Listed in alphabetical order*

**Jeffrey Covington, MPH**  
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**Clint Hurdle**  
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**Dini Rao**  
**Marguerite Rupnow, MBA**, Chair

**Ann Scheimann, MD**  
**Denise Servais**, Secretary  
**Michelle Torbert**



# STORIES OF PWS

*Click on the images to read/watch these inspiring stories*



VICTORIA



KHALED



ANDREA



JACOB



MIRA



BOOTHIE

## SPOTLIGHT ON PWS



Our **Spotlight on PWS** series strives to share the everyday moments of our loved ones with PWS - we want to know more about individuals with PWS, celebrate with them, share in the frustrations, and provide support when and where we can. The experiences shared here can help others learn how to meet similar challenges with more preparation or might inspire others to see their goals through. Click the button below to read these stories.

[READ MORE SPOTLIGHT ON PWS STORIES](#)



# MARKETING ANALYTICS

## FOLLOWERS

	16,088
	2,763
	1,519
	2,483
	1,179

## PWSAUSA.ORG

**Avg. Monthly Visitors**  
23,781

**Avg. Monthly Page Views**  
48,893

**Avg. Engagement Time**  
1:43

## BLOG

**Avg. New Monthly Posts**  
14

**Avg. Monthly Post Views**  
3,161

**Avg. Monthly Readers**  
275



## PODCAST LISTENERS

**New episode shared across all Podcast streaming platforms every Tuesday**

10,528 Total Episode Downloads  
462 downloads on top episode  
On average, 180 listens per episode

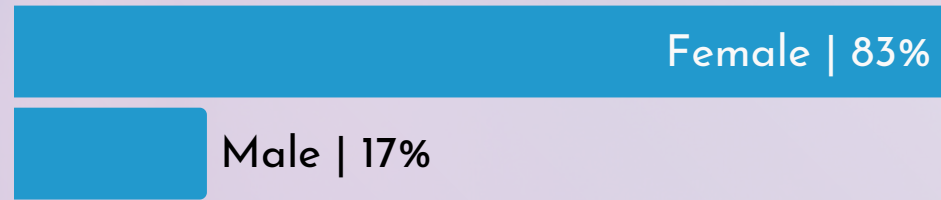
*PWS United Podcast launched in August 2024*



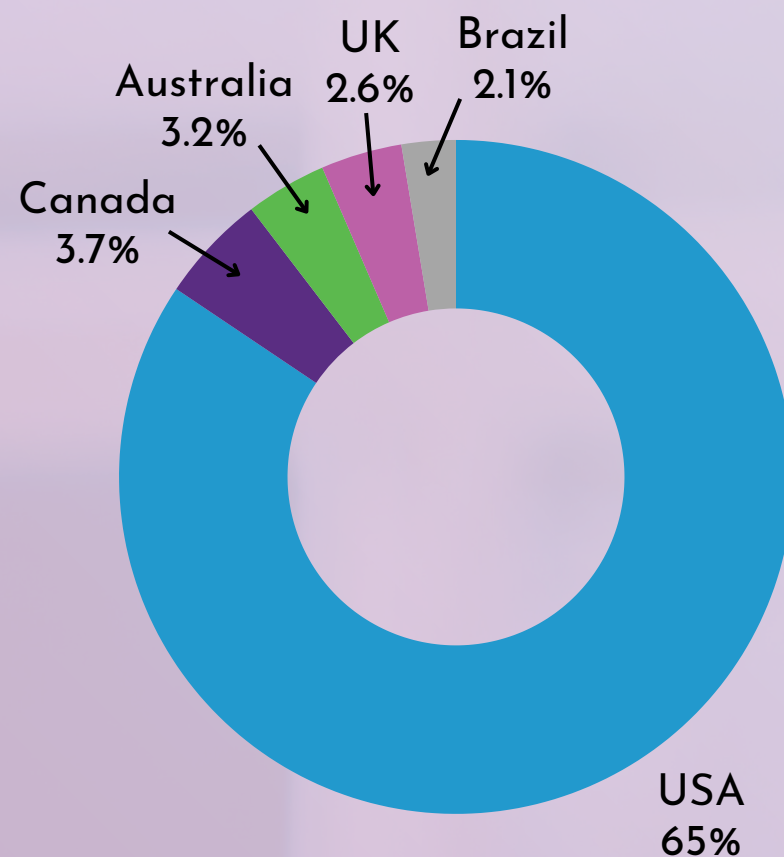
# MARKETING ANALYTICS - DEMOGRAPHICS

## SOCIAL MEDIA FOLLOWERS

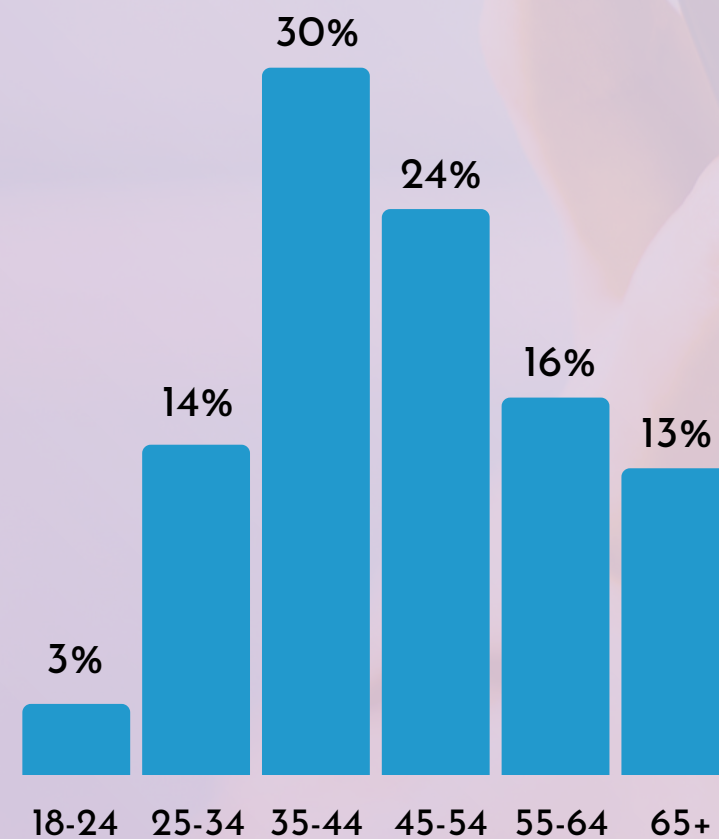
Gender



Countries  
(Top 5)

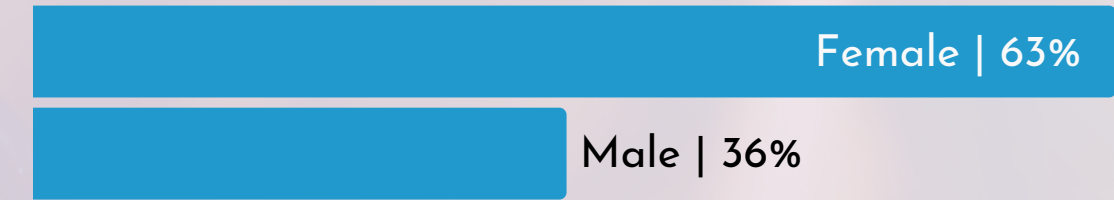


Age

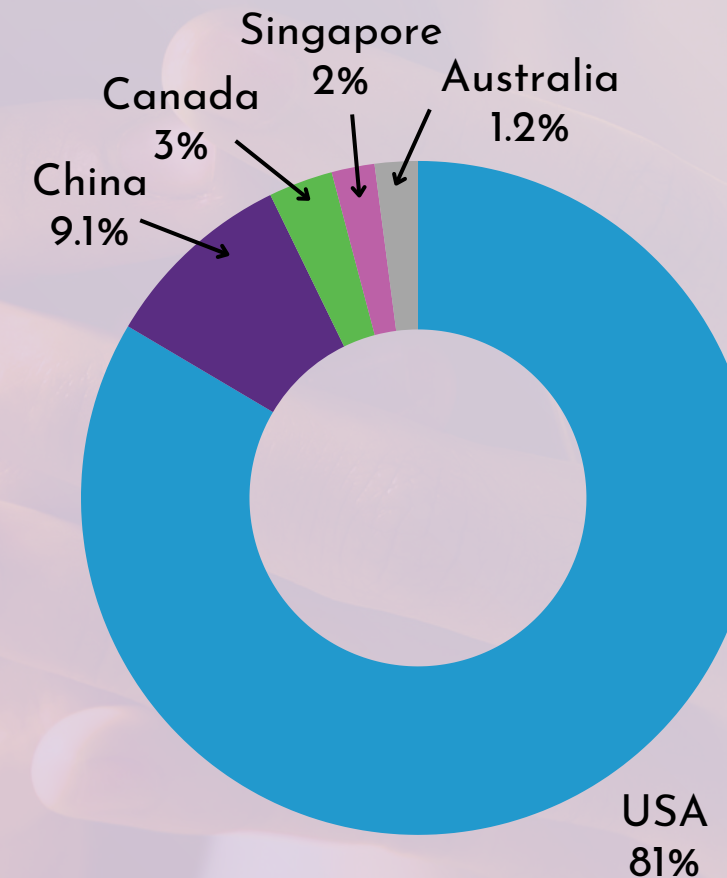


## WEBSITE VISITORS

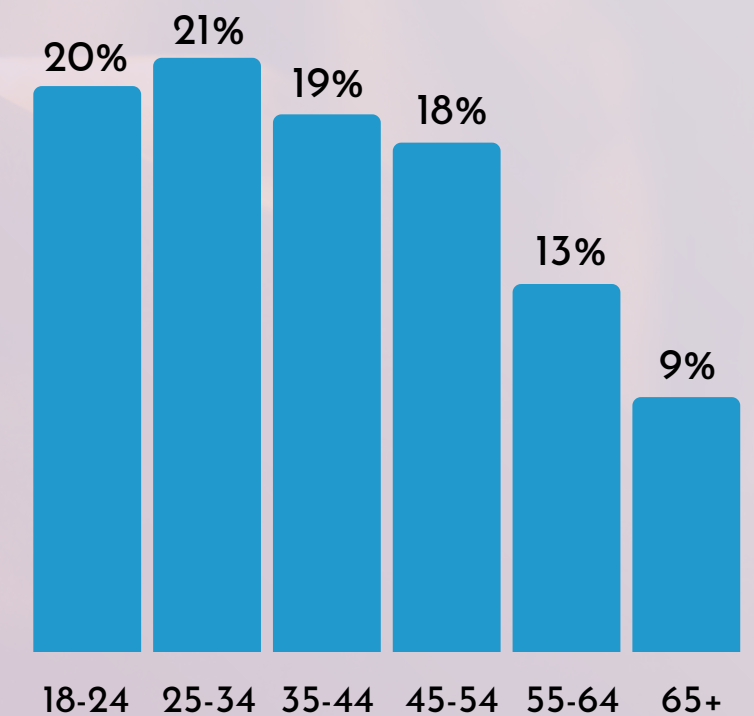
Gender



Countries  
(Top 5)



Age





# SUB-BRANDS OF PWSA | USA



PWSA | USA's Podcast

[LEARN MORE](#)



Peer-to-Peer Fundraising

[LEARN MORE](#)



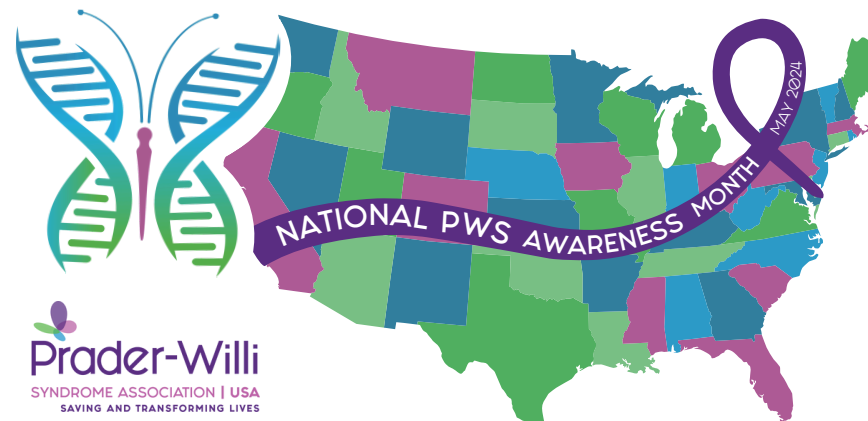
Advocacy Efforts

[LEARN MORE](#)



Annual Fundraising Drive

[LEARN MORE](#)



PWS Awareness Month (May)

[LEARN MORE](#)



ECHO 4 PWS: Healthcare Provider Series

[LEARN MORE](#)



# PWSA | USA EVENTS



PWSA | USA 2027  
NATIONAL CONVENTION

Biennial Conference

[LEARN MORE](#)



D.C. Fly-In

[LEARN MORE](#)



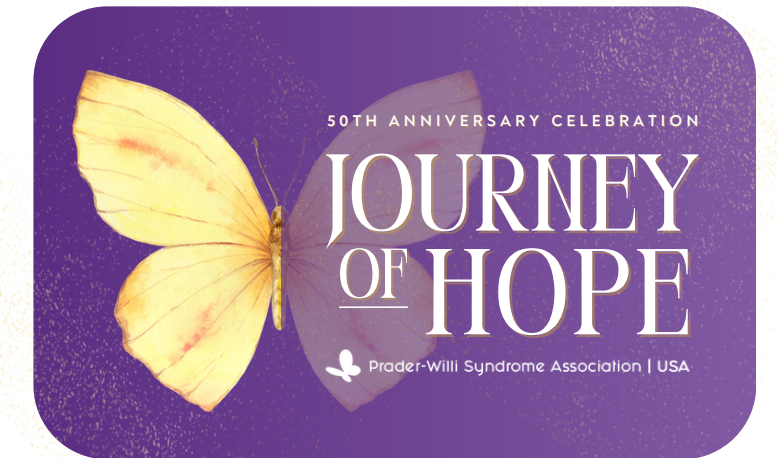
Moms' Retreat

[LEARN MORE](#)



Residential Providers Conference

[LEARN MORE](#)



50th Celebration: Journey of Hope Gala

[LEARN MORE](#)





# 2026 EDITORIAL CALENDAR

EMAIL, SOCIAL MEDIA, PODCAST, BLOG SCHEDULE						
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
PWS Hope United fundraiser/event social media post	Monthly focus community prompt social media post	PWS United Podcast episode release  Standalone emails sent (event, campaign, program focuses)	Ask Nurse Lynn question/answer blog article	Resource spotlight social media post	PWSA   USA Pulse Newsletter (emailed bi-weekly)  New Family Support blog article  Community-contributed blog article (first Friday of every month)	Spotlight on PWS social media post

PWSA | USA's 2026 editorial calendar is packed with exciting content designed to inform, inspire, and unite the Prader-Willi syndrome community. From social media campaigns and podcast episodes to email updates and blog articles, we're committed to sharing stories, programs, and resources that make a difference.

If you have a program, service, or information you'd like us to help spread the word about, we'd love to collaborate! Reach out to our communications team at [communications@pwsausa.org](mailto:communications@pwsausa.org) to discuss how we can amplify your message through PWSA | USA's platforms. Let's work together to create greater awareness and support for the PWS community in 2026!

EVENTS, FOCUSES, CAMPAIGNS BY MONTH			
JANUARY	FEBRUARY	MARCH	APRIL
PWSA   USA Staff Retreat (Jan. 22-25)  Mental Wellness Month	National Caregivers Day (Feb. 20)  Rare Disease Week on Capitol Hill (Feb. 24-26   Washington, D.C.)  Rare Disease Day (Feb. 28)	Developmental Disabilities Awareness Month  National Nutrition Month  Sleep Awareness Week (March 8-14)  Neurodiversity Celebration Week (March 17-23)  Clint Hurdle Hot Stove Dinner (March 21   Bradenton, FL)	National Occupational Therapy Month  National Siblings Day (April 10)  National Volunteer Week (April 19-25)  Solidarity & Spice: Rasika Wine Dinner PWS (April 25   Washington, D.C.)
MAY	JUNE	JULY	AUGUST
Prader-Willi Syndrome Awareness Month  PWSA   USA's D.C. Fly-In (May 4-6   Washington, D.C.)  PWSA   USA's United We Brunch Campaign  National Nurses & Teacher Appreciation Weeks (May 6-12)	Scoliosis Awareness Month	National Minority Mental Health Month	Gastroparesis Awareness Month  National Make-a-Will Month  PWSA   USA's Residential Providers Conference (Aug. 21-22   Savannah, GA)  PWS United Podcast Anniversary (Aug. 31)
SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER
Newborn Screening Awareness Month  National Service Dog Month  Direct Support Professionals Week (September 6-12)  World Physical Therapy Day (Sept. 8)  World Narcolepsy Day (Sept. 22)  Prader Silly: A Night of Rare Laughs (Sept. 30   Nashville, TN)	National Physical Therapy Month  16th Annual Hunter Lens Golf Tournament (Lakeville, MA)  World Mental Health Day (Oct. 10)  PWSA   USA's Moms' Retreat (Oct. 16-17   Park City, UT)	PWSA   USA's Angel Drive Campaign  National Family Caregivers Month  International 15Q Day (Nov. 15)  World Prematurity Day (Nov. 17)	PWSA   USA's Angel Drive Campaign  Giving Tuesday (Dec. 1)  International Day of Persons with Disabilities (Dec. 3)



# LEARN MORE ABOUT OUR WORK

At PWSA | USA, we're here to support, collaborate, and share the stories that matter most to the Prader-Willi syndrome community. Whether you're seeking information, want to help spread awareness, or explore partnership opportunities, we'd love to hear from you. No request is too small - reach out today and let's make a difference together. For media inquiries, please email [communications@pwsausa.org](mailto:communications@pwsausa.org) or call (941) 312-0400.



**(941) 312-0400**



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